Support from your GP

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Introduction

To diagnose ME – or send you to a specialist for a diagnosis – your GP will need to know what symptoms you've been experiencing.

It can be hard to remember everything when you're put on the spot, especially given that there are a range of symptoms associated with ME, including difficulties with memory.

By doing a little bit of preparation for your appointment with your GP, you can help yourself – and your doctor – feel more confident and comfortable.

UK charity The Patients Association (Tel: 0800 345 7115) offers information and guidance to help you access and make sense of the health and social care services you are entitled to.

Preparing for your appointment

If possible, arrange appointments for your best time of day and rest beforehand so you feel as ready as possible.

If you have several things you want to talk about, you could ask about booking a double appointment.

There can often be a lot of information to remember, so it can be helpful to have someone with you to listen to what is being said and to make notes.

You can choose to take a parent, carer, other relative or friend into the appointment with you.

Some people like to prepare for their GP visit by recording their symptoms as they experience them in the days leading up to the appointment or taking their pacing diary with them.

This can help you understand what is going on and enable you to reflect on your own particular circumstances.

The effects of ‘overdoing it’ may not show up for a day or two but your diary may help you to identify what triggered your symptoms.

Because time will be limited when you see your GP, it is helpful to clarify the purpose of your visit and what you want to achieve at the beginning of the appointment.

Consider what questions you want to ask (see below) and write them down before you go in. Make sure you understand everything your GP has told you before you leave the surgery.

Don’t be afraid to ask them to explain anything you’re not sure about. It is important that you understand how to manage your care

If you develop any new symptoms or health issues it is important that you discuss these with your GP so that they can assess whether the symptoms are part of your ME or are caused by something different. They may be able to see a link which is not obvious to you.

Remember that your GP is experienced at pain relief and other symptom management.

You may have to remind them that the NICE guideline for ME advises healthcare professionals to (section 1.12.17): “Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment. Consider:

- starting medicines at a lower dose than in usual clinical practice
- gradually increasing the dose if the medicine is tolerated.

During the appointment

At the beginning of your appointment, it might be helpful to be clear about why you are there, and what you want to get out of the visit.

It helps everyone if you are specific about the problems, then prioritise them, for example: "Of all these things the one that concerns me most is…" or "I think I would cope better if my sleep pattern improved."

Some useful questions for you to ask your doctor might be:

- Which tests have you (and any specialists involved in my diagnosis) carried out and what were the results? Is this the full list of tests recommended in the guidance? The 2021 NICE guideline for ME advises which tests should be carried out along with a medical assessment (including symptoms and history, comorbidities, overall physical and mental health), physical examination and an assessment of the impact of symptoms on psychological and social wellbeing.

- Are all my symptoms related to ME or could I have an additional (co-morbid) condition or illness?
- Have you ruled out other conditions before giving me a diagnosis of ME?
- Not all symptom-management approaches are effective for all patients. How do we know what's right for me?
- Are there medications that might help alleviate the symptoms that are troubling me particularly at the moment?
- Does a specialist NHS ME service exist locally that you can refer me to?
- If not, is there a local consultant with an interest in ME who could see me?
- Are there any self-management courses available through the NHS locally for people with ME or long-term conditions?
- Is there any equipment, aids, adaptations or similar eg. a wheelchair, disability travel pass, Blue Badge or stair lift that could help me maintain my independence?
- Would a referral to the local authority social care department for advice and an assessment be helpful? (their role is to support you)
- What can I do to help me self-manage my symptoms?
- After my diagnosis has been formalised and my treatment/management plan has been established, how frequently should I come back for monitoring and review
- Are there any 'red flag' symptoms I should alert you to straight away if they develop or get worse?

It's important to be yourself - don't perk up or put on a special effort if that's not how you usually are. Your doctor needs to see how you are really feeling.

Some doctors might ask a lot of questions, because they are trying to build an accurate picture for themselves as quickly as possible.

By answering them as fully as you can, he or she will get the best picture of how your symptoms affect you.

Trusting your doctor

It's important for you to feel that you can trust people who have a significant role in your life.

If there is poor communication, or you doubt the doctor understands your condition, this can be confusing - your brain tells you that the professional knows better than you, but your gut feeling tells you otherwise.

If you feel let down by your doctor, this can make you begin to doubt yourself and stop trusting in your own instincts. This may affect the way you behave – you might become aggressive, withdrawn, angry or reckless – but this won't help you receive better care.

Making your feelings clear can help you take control of the situation.

You may still end up disappointed with your doctor, but making a plan and carrying it through is good for your self-esteem and will improve your psychological health.

Getting your point across

It can help to use names as a reminder that there are real people involved.

Say "Doctor Smith" not "Doctor" and "Debra" not "my daughter" (if you are a parent/carer).

Ask for the names of any specialists to whom your doctor refers you.

If a carer is talking on your behalf, it's more effective for them to focus on their own needs, rather than speaking for you.

For example, say: "I'm worried about Debra and would feel reassured if she saw a specialist," not "Debra needs to see a specialist" or "You need to refer her to a specialist."

Few people respond well to being told what to do, but no-one can argue with your needs as you express them.

Don't be afraid to disagree with your doctor or say you don't understand.

Calmly explain why you disagree or ask questions to help you understand better. You can ask them to repeat or explain things to you more simply.

Make sure you understand everything your doctor has told you before you leave the surgery. If you would like to try a symptom management approach you've heard about, ask your doctor what they think of it and listen to what they say before making a decision.

You have the right to turn down any treatment or symptom management approach if you think it is unsuitable for you.

However, it is best to listen to your doctor's reasons for suggesting the treatment before you refuse. Conversely, don't just accept everything that is offered without taking time to think it through or researching the treatment.

You might find it useful to say to your doctor: "I will think about that over the next week/month and tell you what I think next time."

If you are meeting unreasonable resistance, the "broken record" technique might be helpful.

This involves repeating your key message while acknowledging any arguments your doctor raises:

You: “I’d feel reassured if I saw a specialist.”

Doc: “A specialist still cannot cure ME.”

You: "I realise that, but I'd still feel reassured if I saw a specialist."

Doc: "I doubt the specialist would find anything different to what I have found."

You: "I understand that but I'd still feel reassured if I saw a specialist."

When you have responded in this way three times and are still meeting resistance, you can change tack and ask: "What are you suggesting as an alternative if I do not see a specialist?"

Action for ME has information for professionals that you could share with your GP and other doctor - the most effective way to do this is to say: "There is an organisation that supports children and adults with ME that has useful, evidence-based information. To save you the trouble, I can leave the contact details for Action for ME with your receptionist."

If you’re unhappy about something

Don't bottle it up. Calmly work out why you are unhappy (be specific) and write down the reasons (be concise).

It is unreasonable to expect your doctor to guess that you are unhappy, so if you want your doctor to know you are upset, make an appointment to discuss it or contact them by phone or letter.

Try to be diplomatic: you will only make the situation worse if you make your doctor feel like they are being criticised or attacked.

If it's not important in the long term and you don't want to talk to them about it, try to put it down to experience and move on. It can help to talk to someone else close to you who understands your illness, so that you can share your feelings.

NHS England patients can read more about making a complaint, including your right to NHS complaints advocacy.

NHS Scotland patients can find out more about the patient charter, communication and consent, and feedback/complaints.

Changing your doctor

You have the right to change doctor if yours isn't supportive. Bear in mind that doctors have the right to refuse to take you on as a patient.

Don't search for the impossible – no doctor has a cure for ME.

If you would like to look for a new doctor, your local ME support group might be a useful source of information and experience. And remember, changing doctors doesn't necessarily mean changing practices - doctors within the same practice often have different opinions and attitudes.

Your own GP may suggest a colleague he/she knows who has an interest in ME.

It might be possible to arrange preliminary appointments with a prospective doctor so that you can ‘check them out' first. It might be helpful to write a brief history of your illness and symptoms for your new doctor, so you don't have so much to go through at the initial consultation.

Give your new doctor a chance – it takes time to build a relationship.

Don't be put off if the doctor doesn't know about ME – it doesn't mean they are a bad doctor. If they are friendly, supportive and open-minded, they will learn as they go along. And if you are unfortunate enough to have had a bad experience with one doctor, remember that every doctor is different.

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